

FACING FACTS: THE ROLE OF EPIDEMIOLOGY IN REPRODUCTIVE RIGHTS ADVOCACY

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MS. FREEDMAN: Our collaboration as a lawyer and an epidemiologist has been, at its essence, interdisciplinary. In that sense, I would agree with Jonathan Mann who, at the Harvard Health and Human Rights Conference, commented that it is sometimes, or perhaps always, harder to talk across disciplines than across cultures. In fact, as a lawyer and an epidemiologist, we may not coexist in total harmony, to use Elizabeth's words, but we do work together with a kind of creative tension. Indeed, that is why we called this talk "Facing Facts," because our exchange is often a process in which each of us is forced to face the facts exposed by the other's discipline.

Sometimes this results in a contentious and frustrating kind of exchange, in which one of us urges the other to just "get real" about what is going on in the world. Luckily, in the end, we always end up having lunch together again and talking more and working more, because, in fact, in the end, both of us—as a lawyer, as an epidemiologist, as women—care very deeply about the very same things—about the lives of women, their well-being, and working towards a world in

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which women can live with health and dignity as full and equal human beings.

We think our collaboration is, in fact, indicative of some broader trends within our movements over the last five to ten years. These two movements, the women's human rights movement and the women's health movement, have been moving along parallel tracks with some occasional cross over. When I say "parallel tracks," I do not mean simply in the kind of visual geometric sense of railroad tracks in which the two sort of move separately without connecting. There has been a parallel movement in the substantive sense.

Both movements are working towards rejecting a view of the world that sees each person as an individual, solitary self armed with rights, who has a body that gets sick or gets well, who is detached from the world in which he or she lives, and who functions in opposition to collectivities. Both movements are embarked on a process of constructing and understanding a connected self, both socially and literally physically—what some of my colleagues like Rosalind Petchesky and Rhonda Copelon have called an integrative principle that works in both fields.

In the women's human rights movement, what we have seen in the last five years, through the Vienna process (the 1993 World Conference on Human Rights) and the Cairo process (the 1994 International Conference on Population and Development), is the effort to go beyond civil and political rights, indeed, to go beyond the first layer of analysis in which we really focused on violence against women and showed how the traditional human rights field had missed women's experience of violation (even violations that were "classic" human rights violations, such as violations against the physical body by agents of the State). Especially with Cairo, the women's human rights movement is now expanding and deepening its analysis, and women's health, especially reproductive health, is an important theme around which that is happening. The women's human rights movement in this field, for example, is working hard on questions of the indivisibility of civil and political rights on the one hand and economic, social, and cultural rights on the other hand.

Just to give an example in practical terms, we see that reproductive rights cannot be understood simply as free choice in a vacuum. After all, it does not mean a lot to have a theoretical right to contraceptives, if there are no contraceptives. Moreover, a theoretical right to contraception means nothing if, in reality, your family or your husband have the power to prevent you from exercising that right. The human rights movement, therefore, is moving towards this type

of analysis that sees the interconnection among different kinds of rights.

At the same time, we see parallel movement in the health field. Early work in the health field focused on health as biological processes, the biological processes by which we define health and disease. In this context, two decades ago and longer ago than that, women's health was largely a concern of the child survival movement. In other words, the reason we needed to have healthy women was because we needed to have healthy mothers in order to have healthy children. This was the approach to women's health, and maybe some of the measures taken in the health field did improve women's physical health but did little, perhaps, for their strategic interests.

This approach began to change around 1985 when the health field began to give increasing attention to women's health, for its own sake. For example, in that year, my colleague, Deborah Maine, together with Allan Rosenfield, looked at what is called the maternal child health field (MCH Field), and asked in an article they wrote in *The Lancet*, the very simple question: "Where is the 'M' in MCH?" In the last decade or so, we have seen the development of the reproductive health movement in which people like Dr. Fathalla have really been so central in defining what the term "reproductive health" means.

With the growth of the reproductive health movement, we see two broad trends in the health field, which are reflected, for example, in the Cairo Document. First, women's health is important in its own right, because women are not just mothers of children, but they are important, valuable members of society in their own right. Second, women's health cannot just be understood as biological processes, but we have to see biology as embedded in, and deeply influenced by, social, economic, and political conditions that affect everyone's everyday life in societies around the world and at all levels—family, community, and state.

In sum, both of these movements—the women's human rights movement and the women's health movement—are working at expanding the context and seeing connections. It is important that we maintain these trends, but—and here is where our collaboration comes in—we should also see warning lights. We should hear bells ringing warning to us, because one of the things that has happened is that we have identified so many connections and so much complexity that we are, indeed, in danger of losing our way.

Both fields have become so complex and so interconnected that we simply don't know where to start. We look at every health condition and try to determine whether it is caused by lack of education,

poverty, women not being able to generate income, not being able to control income, lack of services, bad laws, lack of law reform, or lack of good courts. We can point to a zillion things which could be the cause of the situation but have little idea how to prioritize among them, how to determine what factors are most influential, and most importantly, where, strategically, as activists, we should start. This is one of the senses in which I think we are in danger of losing our way.

The second sense is one that Deborah and I spend most of our lunch hours talking about. We are worried that human rights people, perhaps because of the complexity that exists at an international level, are beginning to use facts very loosely. Perhaps the best example of this is one of the most contentious, and that is contraception. You will regularly hear people who are not in the health field saying that particular contraceptives are dangerous, or have never been tested on different populations. Very often, these statements are simply detached from the real facts of how the contraceptives are tested. It might not be the ideal kind or highest quality of scientific testing, but in international law discourse we are not attuned to real facts. This loose use of facts may be fine for organizing. In fact, I think we have done very well developing a movement. But, if you don't have your facts right or you don't respect the facts you will not be taken seriously by the people who have the power to initiate changes in these different fields.

Moreover, this loose and undisciplined approach does not work for getting things done, for deciding where do we go from here. I don't want to blame just the rights people for this, because, indeed, I think if we look around, we see that the health people or the health policy people have also been playing fast and loose with the rights language. In fact, we in the women's human rights and women's health fields have been so successful that it seems everybody is talking about rights, and what used to be called "family planning" is now routinely called "reproductive health."

I think, indeed, many of our adversaries are endlessly creative. Some of you might have seen the little, tiny article in *The New York Times* about the Vatican's "revolutionary" document on Beijing, in which the Vatican came out and said we ought to start paying women for the housework they do. Then, of course, the Vatican goes on to observe that women should stay home and take care of their children, because that is their rightful place. I think we have to be really alert to the endlessly creative ways in which our own language gets used.

Deborah and I spend a lot of time worrying together about this kind of looseness, and therefore, we decided to call our collaboration

"Facing Facts" because we need to face each other's facts. The facts do not always show what we want them to show, or indeed what we expect them to show.

Just as there is a trend of seeing rights not just as individual cases of abuse but as embedded in broader structural systems of injustice, we also need to see health, not just as individual cases of disease, which is really the work of medicine. Rather, as we are looking at rights structurally, we need to look at health structurally. We need to look at, not so much the field of medicine, but rather the field of public health, the health of populations. The primary analytic tool of public health is epidemiology. In this short presentation, Deborah and I want to take one very big problem in the field of epidemiology and in the field of women's human rights—maternal mortality—and show you what we think it means to be facing each others' facts.

MS. MAINE: Epidemiologists may feel that reproductive rights advocates speak in grand generalities and do not pay enough attention to facts. Furthermore, these two disciplines do not always even speak the same language, as, for example, when Lynn and I talked about implementation. For Lynn, implementation means going from law to policy. For me, implementation means going from policy to programs.

Despite its difficulties, collaboration is imperative, especially now when policies are being developed. The work we have embarked upon—by "we," I mean all of us here—is too important to risk failure. Failure can mean having a policy that does not actually benefit women in the world. This kind of failure is not a remote possibility. It could happen if policies and programs are based just on common sense or on widely accepted ideas, because common sense can be misleading and widely accepted ideas are sometimes wrong.

An excellent example is, as Lynn said, maternal mortality. Maternal mortality is the death of women due to complications of pregnancy. This includes complications of abortion. The death can take place before delivery, during delivery, or after delivery, up to about forty-two days, but must be directly due to pregnancy or some medical condition that was aggravated by pregnancy.

Deaths from complications of pregnancy are extremely rare now in developed countries. But in less developed countries, obstetric complications are still the leading cause of premature death among women. The situation is best expressed through a statistic called the lifetime risk, which is the average cumulative likelihood that a woman will die of a maternal cause. This reflects both the risk associated

with each pregnancy and the number of times the woman gets pregnant. A person cannot accumulate infant mortality risk because you are only an infant once. But a woman accumulates the risk of maternal death every time she gets pregnant.

The lifetime risk of maternal death in Africa today is 1 out of 23 women. It is a risk much higher than AIDS in most places except for perhaps central Harlem. In Asia, the risk is 1 in 54 and in Latin America, 1 in 73. By comparison, in Northern Europe, the risk is 1 out of almost 10,000 women. One in 23 versus 1 in 10,000. That is a tremendous difference.

We are accustomed to seeing data showing large differentials in health conditions between developed and developing countries, though with maternal mortality this difference is much bigger than, for example, with infant mortality. Furthermore, we assume, rightly, that elements of the development process are responsible for these differentials. But which elements? This is the concept that Lynn was talking about when she was discussing setting priorities.

Some people maintain that education is a key element in maternal mortality. After all, many studies have shown that the higher the level of education, the lower the level of maternal mortality. This is true both between countries and within countries. Thus, there is a correlation between maternal mortality and education; they vary together. A correlation, however, is not the same thing as a causal relationship. Just because two statistics vary together does not mean that one causes the other. In fact, on closer inspection, maternal mortality and education are not causally related.

Consider, for example, the history of maternal mortality in now developed countries. In Britain, from 1840 to 1930, that is 90 years, there was no decline in maternal mortality. During this time, infant mortality declined steadily, due to improved nutrition, improved education, improved sanitation, and improvement in the standard of living—in other words, what we call "development."

During this whole time, however, maternal mortality did not decline at all. Why? Moreover, why did it start to decline in the mid-1930s? Maternal mortality at that point dropped sharply, and by 1950 was not a major problem anymore in the West. Starting in the mid-1930s, specific treatments were developed that could save the lives of women who had serious complications—chiefly, antibiotics for infection and blood transfusion for women with hemorrhage.

In trying to understand what will reduce maternal mortality, in addition to international comparisons over time, we can look for international evidence at particular points in time. For example,

education was almost universal in what are now-developed countries, well before maternal mortality began to decrease. In 1915, when maternal mortality was still over 600 deaths per 100,000 live births, more than ninety percent of women in this country were already literate. This is compared to less than 8 deaths per 100,000 live births in the United States today. What kind of a threshold of education, therefore, are we recommending to developing countries?

The point is that education is important for lots of reasons, including lots of human rights reasons, but it is not going to reduce maternal mortality in developing countries. This is one example, moreover, of how it would be possible to win our policy goals, and yet not achieve our health goals.

There are many other examples of this, and some of them challenge cherished beliefs. The scientific literature, for example, does not support the faith in prenatal care that people have in this country.

We must, therefore, be careful not to bend the facts to suit our beliefs or to disregard the facts. It is often said, for example, that female genital mutilation kills many women during childbirth. Experts, such as Dr. Nahid Toubia, assure me that this is not the case. Actually, when you look at the literature, there is not the kind of variation over geographic regions that you would expect to find if female genital mutilation were a chief cause of maternal mortality. Female genital mutilation is, in my opinion, and in the opinions of lots of people who know better, a serious problem, but we cannot justify attacking it on the basis of maternal mortality. Moreover, if we did justify discouraging female genital mutilation on the basis of maternal mortality, we might promote the wrong programs. If female genital mutilation is a medical problem, maybe there is a medical and not a social solution such as doing safer circumcisions and making sure that women deliver in hospitals so that they can be properly sewn up again. I do not think that this is what we had in mind. But that is an example of how, if you have your facts wrong, not only may your program be useless, but you may actually head in entirely the wrong direction and end up someplace you did not want to be.

We must also be careful not to let our own values cloud our judgment and our evaluation of facts. Caesarean section, for example, is a greatly abused medical procedure here and in many countries, including some developing countries, such as Brazil. This is a serious problem from both a human rights point of view and from a medical point of view, because all surgery is dangerous. On the other hand, we must not forget that probably lack of access to

caesarean section for women who have obstructed labor is one of the key causes of maternal deaths in developing countries. Now, we can fight overuse of caesarean section here, but we must remember that lack of access to this procedure is a major cause of suffering and death for women in developing countries. We have to keep our own values from coloring our understanding of other people's situations.

On the positive side, collaboration offers exciting possibilities. For example, there is a lot of important work to be done in what I think of as "feminist epidemiology." Feminist epidemiology doesn't mean that you necessarily even gather new data. Because how you ask a question expresses your values and shapes the meaning of your answer. Consider the following example:

People who are interested in family planning for the reduction of maternal mortality (which is a completely legitimate goal) have wondered how much maternal mortality would be reduced if no women over thirty-five (when the risks start to go up) had babies. Some women over thirty-five, however, have very good reasons to have babies. With existing data, it is possible to ask the same question in a different way. What if women who say they want no more children had no more children; what would be the effect on maternal mortality? You are still looking at the effect of family planning but from a feminist point of view.

In conclusion, collaboration between human rights advocates and public health scientists can benefit both fields. There is, however, a lot of work to be done.